

To Die or Not to Die - Is that the Question? Educating Physicians About End-of-Life Care

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Introduction

The past three decades of technological advances in medicine have produced many benefits in the way of curing illness and prolonging quality life, when applied appropriately in acute injury for disease. However, some of these same developments, when used inappropriately in those conditions associated with degenerate processes without possibility of cure, can lead to prolongation of the dying process with associated poor quality of life. Little is taught in medical and nursing schools, or in residency programs, about end of life care. The difficult decisions to be made by the patient, her or his loved ones, and the medical care team present personal, ethical and emotional quandaries. If physicians are to provide patients with informed answers to questions about avoidance or withdrawal of treatment, palliative care, refusal of hydration and nutrition, as well as discussing options open to the patients wishing to hasten death, much more education in these areas must be included in the training of those who will be treating terminal illness. Many physicians and patients now share the opinion that the continuum of care for such hopeless situations should include physician assisted death as one of the options to be considered.

Discussion

The twentieth century has seen many remarkable advances in technology, most notably in the field of medicine. Much of the progress has taken place in the past 25 years, altering the entire approach to many medical conditions. With these changes, the venue for caring for those with terminal illness has changed from the home to the intensive care units of tertiary care hospitals. Due to this medicalization of dying, it is estimated that over 80% of patients are hospitalized at the time of death, in sharp distinction to the 25 to 40% just four decades earlier.¹

Since the early 1970's, when ventilators became available to maintain life in cases that, without such advanced life support technology, would have little or no possibility of survival, the approach to end of life care dramatically changed. The opportunity to save many patients suffering acute trauma or illness, with accompanying cardiopulmonary compromise, was welcomed. Numerous patients have survived serious illness and injury, returning to active lives, with longevity and quality of life that was close to that expected prior to hospitalization.

There was an insidious development secondary to the rapid number of inventions in the medical sphere. Prior to the advent of this technology, it was usual to care for terminally ill patients in the home surrounding, after exhausting the limited armamentarium of life-sustaining therapies then available. If life expectancy was measured in only weeks or months, compassionate attention to comfort of the patient was the norm, with analgesics freely prescribed to ensure adequate pain control. However, in the effort to prevent death in those for whom there was "no more to be done," the technology that had been developed for short term use in acute,

remedial situations, was increasingly applied to patients suffering terminal malignancies with widespread metastases and those with severe neurological damage. The latter included cerebrovascular accidents and head trauma with deep, permanent coma, in what came to be called persistent vegetative state. This misapplication of technology lead to an ever increasing number of patients totally dependent on ventilators and/or other life-supporting medical devices, with no hope of recovery.

As life expectancy increases due to improved nutrition, health habits, and medical progress in available treatments for preventing or curing many infectious illnesses, the number of older Americans who suffer malignant disease has also increased. When in terminal stages of cancer, as well as with some neurological conditions, such as Alzheimer's disease and amyotrophic lateral sclerosis, it appears that the patient is frequently ready to accept the inevitable conclusion of such illness before the physician may be willing to discontinue efforts to extend life. Technology may be applied to these chronic disease states when it is clear that no cure is expected, and that no possibility exists of the individual returning to a quality of life acceptable to her or him.

Unfortunately, little in the medical curricula of most universities helped prepare physicians for these situations. In reviewing textbooks considered to be the best available in their fields, there is great attention paid to details of diagnosis, prognosis, medical and surgical treatment, and technological applications for even the rarest of conditions. There is, however, virtually nothing included about what to do for the patient when further curative efforts are futile. Personal investigation and conversations with faculty of medical schools and residency programs revealed that few medical schools have any required courses dealing with dying and death. Some have a few "interest" lectures on the subject, but required courses are rare. Similarly, very few residency programs expose the young physicians to such rotations as long-term facilities or hospice care.² There are a few that have the opportunity to follow a patient or two in a hospice program, but no compulsory exposure to terminally ill patients in long term care facilities or home hospice care is found in the vast majority of residents training, even in the oncological specialties. Until very recently there were few continuing education programs sponsored by organized medical groups, or by hospital staffs, that included presentations discussing end of life care. In November, 1996, the AMA ethics division announced that a program to teach physicians skills for quality end-of-life care is being organized.³ This appears to have happened only after that organization became alarmed at the success of grass roots efforts to effect changes in laws that would permit some patients, with no hope for recovery, the option of requesting assistance in shortening the time of dying.

As a result of the paucity of efforts to teach physicians about dying and death, the numbers of patients who died while still connected to life-supporting equipment seemed ever-increasing. The SUPPORT

study reported in *JAMA* confirmed much of what is wrong with the care of terminally ill patients.⁴ Physicians either did not know, or failed to follow, the wishes that patients had expressed verbally or in advance directives. As a result, many of the cases followed revealed continued application of technology not desired by the patients, yet with a surprisingly high percentage suffering pain in the last week of life. Even with the expenditure of millions of dollars of grant money in an effort to intervene, with specially trained nurses advising the physicians as to patient preferences, no improvement in physician behavior or in the dismal results occurred.

Clearly, those in didactic medicine need to redirect some of their efforts to teaching appropriate care for those with incurable illness. It is the opinion of many physicians and the majority of patients that those who are dying with chronic disease, for which all available methods of treatment have been considered and/or undertaken, and for whom the very best in palliative care has failed to provide the quality of life that the patient finds acceptable to continued existence, that another option could and should be offered. That option, as an alternative to continued suffering secondary to the prolongation of the time of dying due to the application of various futile treatment modalities, is physician assisted death. The few patients for whom palliative and hospice care does not suffice deserve this consideration. The United States Court of Appeals for the Ninth Circuit, which encompasses all nine western states, agreed with this contention, by a majority vote of 8 to 3, in a decision filed on March 6, 1996. The final paragraph of the majority opinion states succinctly that an individual has the right to make decisions affecting life and death. That Court also dealt with the proscription placed on such action as hastening the time of dying by those with strong religious beliefs that "only God can take one's life." The Justices stated that "Those who believe strongly that death must come without physician assistance are free to follow that creed, be they doctors or patients. They are not free, however, to force their views, their religious convictions, or their philosophies on all other members of a democratic society, and to compel those whose values differ with theirs to die painful, protracted, and agonizing deaths."

Although there is much to be done in the way of improving teaching about end of life care and decisions, there is some recent improvement apparent in the awareness of physicians about patient preferences with regard to terminal care. It is my belief that the increasing dialogue in our society, and in medical circles, regarding terminal illness, has resulted from the demand, by certain patient advocacy organizations, that more autonomy in decision making be offered to patients. It has been reported that more attention to teaching about palliative care, pain management and the need for earlier and more frequent hospice referral, is occurring in Oregon. This may be attributed to the extensive exposure of all the citizens in that state to the arguments, both pro and con, preceding the passage of Measure 16 in November 1994. When the injunctions preventing implementation of that law are finally resolved, there will be an opportunity to establish guidelines and safeguards for physician aid-in-dying. Hopefully, with improved teaching about end of life care for all health care professionals, the number of patients who fail to have a quality of life deemed by them to be commensurate with continued life, will be minimal.

References

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Editors Note:

Richard MacDonald, MD, since his 1993 appointment as Medical Director of the Hemlock Society USA, researches and writes on medical aspects of physician aid-in-dying, provides guidance on medical matters to the National Board of Directors and to local chapters, and creates dialogue and increases communication between Hemlock and the medical community. Born and educated in Canada, he has practiced family medicine in Canada and California for over forty years. Extensive experience in communications has included his "Doctor of the Air" program on the Canadian Broadcasting Corporation and, more recently, on KPAY, Chico, California, and a "Health Break" series for local television. Participation in many national medical organizations meetings will advance the mission of Hemlock by educating the medical and allied health professionals in the concepts of appropriate end-of-life decisions to provide their patients with the choice of death with as much comfort and dignity as possible. Included in his current memberships are the Society of Teachers of Family Medicine, The Gerontological Society of America, the American Association of Bioethicists and the Society for Health and Human Values. He has traveled extensively for Hemlock, speaking to both medical and lay audiences, concentrating especially on delivering presentations to medical students and residents who will be involved in treating patients with terminal illness. As this "most important bioethical issue of the 1990's" continues to be debated in both medical and lay circles, he will be expressing the philosophy of the Hemlock Society USA and hopes to see improved care and caring for those with terminal illness, with more adequate pain control, earlier and more frequent referral for hospice and palliative care, and the possibility of the choice of physician aid-in-dying for those few patients for whom even the best care fails to provide a quality of life acceptable to the dying patient.

Richard MacDonald, MD and Faye Girsh, executive director of the Hemlock Society—USA, attended the 9th annual meeting of Hemlock USA in Denver, November 9-11. The Conference on Physician Aid in Dying presented the latest developments from legal, medical, legislative, nursing and family perspectives. More on this in later issues of the Journal. Thanks to Dick and Faye and the wonders of e-mail and faxes, we have their manuscripts for this special issue. Mahalo again, Dick and Faye.

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in these final days of life, such as the need for spiritual, legal and other counselors. The medical services represent only a portion of what each patient needs in navigating this final passage of life.

To ensure satisfactory closure involved in this process of letting go for everyone, it is critical that the physician spend sufficient time to advise, reassure, support and comfort not only the patient, but must also extend these services to the family and other survivors as well.

Suggested Reading

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